

Gold Star Awaits Dr. Shirley

She had many names, the “Little Doc,” “Dr. Spinal Cord,” the “Little General,” but there were few who didn’t recognize Dr. Shirley McCluer. Diminutive in size, she made up for it in spirit. When Dr. McCluer died on December 2, 2006, at age 79, it was the “end of an era” for the spinal cord injury community in Arkansas.

Dr. McCluer began her medical career at LSU School of Medicine. She became a physician in 1955, when there were few women physicians. As Dr. Vicki Stefans, Physiatrist at Arkansas Children’s Hospital noted, “She was a pioneer and a role model, a missionary for a field that used to need missionaries a lot more than it does now. We take for granted the kind of care our patients can have today, but those of us who provide it need to remember that we stand on the shoulders of those who came before.”

She completed her residency at Sister Kenny Institute in Minneapolis, working with polio patients. That training began her long distinguished career as a physiatrist, a specialist in rehabilitation, though she considered herself a paraple-



Dr. Shirley McCluer, former ASCC Medical Director, died December 2, 2006.

gist, a spinal cord specialist. In 1964, she became the Medical Director at the Hot Springs Rehabilitation Center, Arkansas’ first center for rehabilitation. She worked there until 1969.

Over the years she worked in spinal cord injury centers around the U.S. and the world. In 1985, Dr. McCluer returned to Arkansas to join the UAMS faculty in the newly established Physical Medicine and Rehabilitation Department, while serving as the Spinal Cord Injury Unit Medical Director at Baptist Rehabilitation Institute. She had

been integral in the development of the Arkansas Spinal Cord Commission (ASCC) and upon her return became ASCC Medical Director, serving in that role until 1998.

Over the course of her years at BHRI, Dr. McCluer worked with many new spinal cord injuries. “She was the little general,” related Billy Altom, a former patient and Director of the Delta Resource Center. “She had her beliefs and you followed them. She was going to make you independent. She would get after family or friends if they pushed your wheelchair for you.” A tough task-maker, she felt people with SCI should be respon-

Continued on page 7 - see “Shirley McCluer”

ASCC Conference Scheduled

Planning has already begun for the 2007 ASCC conference—and you should **plan to attend now by reserving Friday, June 15, 2007, on your calendar.** The conference will be held at the Ferndale 4-H Center in west Little Rock. The

day’s activities will include plenary speakers, breakout sessions, vendor exhibits, lunch (always a favorite) and door prizes.

Don’t be left out! **Mark your calendar now.**

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SPINAL COURIER

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In Memory of Josh Bateman
Annette and Bob Stacy

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Apply for Scholarships

Dear Readers:

It's time to start applying for educational scholarships. The Governor's Commission on People with Disabilities' deadline for receiving applications is **February 27, 2007**. Call Ida Esh't at **501-296-1637** for your application form.

Nationally, the Spina Bifida Association of America's deadline

is **March 2, 2007**. Call **1-800-621-3141, ext. 23** to ask for an application, or go online to **<http://www.sbaa.org>** to download an application. Locally, the Spina Bifida Association of Arkansas' deadline is **August 15, 2007**. To request your application, call Vicki Rucker at **501-978-7222**.

Dee Welsh
Coeditor, Spinal Courier

From the Director

It's a new year—they just seem to come faster and faster for me!

As you read this, Arkansas will have a new Governor. But Mike Beebe isn't new; he has served in the Arkansas Senate for over 20 years and as our Attorney General. This means that Governor Beebe already knows about Medicaid and Medicaid fraud, the lack of accessible transportation in our state, the need for community-based personal care assistance and many of the other issues that face folks with disabilities in Arkansas. He has worked on these issues for years, and will continue his work as the leader of our state.

This month, the Arkansas Legislature convenes in Little Rock to make laws, set budgets and determine programs for our state. Some of our State Representatives and Senators are new, while some have years of experience. These folks represent you and me and all other Arkansans. Get to know your Senator and Representative—let them know your views and concerns. Make your voice heard on topics that interest you. It's your right and your responsibility.

Happy New Year!

Cheryl L. Vines

In Memory of Harold Thomas
Murray and Ken Johnson

In Memory of Lee Brody
Linda and Ralph Riley
Angie and Tony Rupp

ASCC accepts tax-deductible donations. The generosity of the many individuals and families who over the years, have made memorial donations is greatly appreciated.

Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517 (voice) / 501-296-1794 (TDD)**, or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

Split Second Decision Program

By Laurie Defoor, ASCC Health Educator

Laurie Defoor is the new Coordinator of the ASCC Split Second Decision prevention education program. She holds a Masters Degree in Health Education, as well as other aspects of the health field.

Each year over 100 Arkansans sustain spinal cord injuries (SCIs), changing their lives forever. The majority of SCIs are caused by motor vehicle crashes involving young men, 15–30 years of age. Nearly all of these injuries could be prevented by good decision-making and use of seat belts. In over 60 percent of Arkansas SCIs seat belts were not in place, and in a third of the cases alcohol was involved.

ASCC and the AR State Police Highway Safety Program, with funding from the National Highway Traffic Safety Administration, have developed **Split Second Decision**, a prevention education program. The Split Second Decision Program is patterned after the national Think First initiative targeting young adults who are the greatest risk. The program is designed to promote good decision-making and safety behaviors in teens and young adults.

ASCC Case Managers and Health Educator, who coordinate the program, introduce the program and discuss the problems in our state. A short video is shown and is followed, whenever possible, by a presentation from a first responder (e.g., State Trooper or Emergency Medical Technician). To conclude the program, a personal testimonial is given by an ASCC client who has sustained a motor vehicle related spinal cord injury.

These personal testimonials have proved to be moving and have the capacity to change the listeners' perspective since they can readily identify with the speakers that are from their own hometown or local area. Those ASCC clients who have participated in the program are proud of their efforts and, as one ASCC client volunteer said, "If I can just get one young person to listen and change his behavior then I have succeeded."

The presentations are popular at colleges, for freshmen orientation and Safe Spring Break and Alcohol Awareness weeks. Also, presentations are made to Driving While Intoxicated/Driving Under the Infl-



Erin Gildner and Laurie Defoor spoke at a recent presentation of the Split Second Decision education program.

ence (DWI/DUI) classes around the state. Last year, 58 presentations were made to 3,037 participants. This year we are increasing our efforts with colleges and are also going into high schools to talk with juniors and seniors.

Along with the presentations, we have promotional events throughout the year. These include posters, which are displayed around the state, and public service announcements to remind people not to drink and drive. If you have any questions or would like to get involved with the Split Second Decision program, please contact Laurie Defoor at **501-296-1788**.

Five State Regional Conference on Spina Bifida

The first regional conference on spina bifida will be held **February 17th and 18th** in Plano, TX, hosted by the Spina Bifida Association of North Texas and the Spina Bifida Association of America. The two-day conference will include national speakers on topics such as urology, secondary conditions, weight management and others. Onsite childcare will be available. This is a great opportunity to learn and meet other families. For additional information, go to **www.sbnorthtexas.org** or call **972-238-8755**.

The Spina Bifida Association of Arkansas will provide scholarships to assist individuals and families in traveling to the conference. For more information, contact Vicki Rucker at **501-972-SBAA (972-7222)**.

New Support Groups

Two new support groups for parents of children with Spina Bifida have been formed and have meetings scheduled for the next three months. You are welcome to attend!

Springdale

First Monday of Month
Jan. 8, Feb. 5, Mar. 5
Jones Center
For More Information:
Maryanne Caldwell
479-521-1463

Little Rock

Second Monday of Month
Jan. 8, Feb. 12, Mar. 12
ASCC Office, 1501 North
University, Suite 400
For More Information:
Cheryl Vines
501-296-1788

Post-traumatic Syringomyelia

By Tom Kiser, M.D., ASCC Medical Director

Nerve tissue, when damaged, heals by leaving a cavity with a surrounding rim of scar tissue. These cavities or cysts can be small and never become a problem or they can grow and become a syrinx, or large cavity, and cause a lot of problems. These problems can occur shortly after your spinal cord injury (SCI) or many years after you were injured. I am writing this article to make you aware of the problems and the many options in managing post-traumatic syringomyelia (PTS).

PTS is a problem for a small percentage of individuals with SCI, but we all need to be aware of the issues surrounding PTS. The exact cause of PTS after a traumatic SCI is not clearly understood. About 50% of patients with SCI will have a small cyst or multiple cysts at the level of the cord injury. A syrinx is noted in only 5 to 8% of patients who will have clinical signs of functional decline.¹ Syrinx enlargement can result from an increase of spinal fluid pressure. This increased pressure may result from coughing, sneezing, straining, weight lifting and manually assisted coughing.

Early signs and symptoms of a syrinx are variable and not specific. Some patients can have a very large syrinx with minimal symptoms. The symptoms are often one-sided at first, but usually become bilateral with time. **Pain is the most common symptom** and usually is located at the initial site of injury, but may radiate to the limbs, neck and back. The pain is described as burning or aching and is usually made worse with coughing or sneezing. The **next most common symptom is ascending sensory**

loss, but increased weakness and loss of deep tendon reflexes are also seen.

Less common symptoms are increased or decreased spasticity, sweating, worsening of autonomic dysreflexia, increased fatigue, and worsening bowel and bladder function. PTS is often suspected after all other causes of the new symptoms are ruled out. **Any change in your neurological findings should be reported to your doctor as soon as possible**, so a workup of the symptoms can be started.

Magnetic Resonance Imaging (MRI) is the gold standard for diagnosis of a syrinx, but there is no consistent relationship between syrinx size on MRI and symptoms. Each case must be evaluated carefully. There are good arguments

The sooner PTS can be diagnosed, the less damage it is likely to do. Thus, suspicious symptoms should be discussed promptly with your doctor.

for both conservative and surgical management and the choice of one method over the other needs to be made after discussing the different options and the possible benefit and risk of each option with your physician.

Conservative techniques involve a restriction of activities, which may transmit venous pressure changes to the cerebrospinal fluid (CSF):

1. Avoid Valsalva maneuvers such as closed mouth straining with transfers, mobility and bowel movements;
2. Avoid the Credé (pushing on bladder) maneuver to empty the bladder; and
3. Minimize manual assist coughing, and forward leans for pressure relief.



ASCC Medical Director Tom Kiser, M.D.

None of these methods have been studied sufficiently, and these recommendations are based on theory and anecdotal evidence.

Some experts recommend conservative management, if there is no apparent or minimal neurological decline. However, some physicians feel that a syrinx will eventually cause some problems at a later date.² So it is important to follow the clinical status of the patient closely and consider surgery if there is significant neurologic decline.

Drainage of the syrinx with a needle through the skin with CT guidance has been used with some success in the past, but there is a reaccumulation of fluid in the syrinx usually within several weeks of the procedure.^{3, 4} Surgical treatment is usually recommended if there is ongoing decline or severe pain. Ideally surgery should be done before there is any clinical weakness, because the weakness may become permanent if there is a prolonged delay before surgery. **Surgical treatments are varied and depend on the neurosurgeons training and experience.** The following is a list of surgical options:

- A. Syringotomy (creating an opening of the syrinx to the space around the cord);
- B. Placing a tube to shunt the syrinx fluid to the:

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Focus On Independence Program Offers Vision Correction Surgery to Quadriplegic Patients

Living with quadriplegia causes many “hassles” in daily life. While glasses are an inconvenience for most people, they can be particularly limiting for quadriplegics. If you hit a bump in your wheelchair and your glasses slip down your nose, you can’t push them up. If you need reading glasses, it’s hard to put them on and off for close work.

But there is help. Refractive Surgeons Robert K. Maloney and Daniel Durrie have teamed up to help launch a national program, called **Focus on Independence**, in which eye surgeons provide LASIK or vision correction surgery at no charge to quadriplegics. This program was recently highlighted in *New Mobility* and *Wheelin’ Sportsman*, both

well-known disability magazines.

According to Dr. Maloney, “For many people glasses are a real nuisance, but to quadriplegics glasses are an additional disability. With the Focus On Independence program, we aim to make day-to-day life a little bit easier for these patients.” The Focus On Independence program is intended for patients over the age of 18, who have suffered a traumatic spinal cord injury and have lost the use of their hands and/or arms, making it difficult or impossible to put on or take off their glasses without assistance. LASIK surgeons from around the country are donating their time and services



to help quadriplegics see without the use of glasses or contacts. **If you are a quadriplegic, and want more information,**

e-mail or call the program with your name, type of injury and the date of your injury. Your case will be evaluated to see if you are a good vision correction candidate. Though the program is headquartered in California, they recruit eye surgeons around the country to do the surgery.

For more information, check the website at www.maloneyvision.com/why/focusonindependence.html, call the Maloney Vision Institute, **877-EYESIGHT** or e-mail focus@maloneyvision.com

PTS

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1. CSF surrounding the cord (syringosubarachoid shunt),
 2. Fluid in the gut (syringo-peritoneal shunt), and
 3. Fluid surrounding the lung (syringopleural shunt);
- C. Improve CSF flow and thus decrease syrinx pressure by surgically enlarging the CSF space (duraplasty) and removing any scarred or inflamed tissue;
- D. Cutting or destroying the spinal cord to prevent progression (corpectomy)⁵; and
- E. Implantation of fetal tissue, olfactory ensheathing cells, etc. (investigational and controversial at this time).

In many cases, surgery is very successful in preventing further nerve damage, which is the primary

reason for doing surgery. Whether or not the nerve damage caused by the cyst before the surgery will recover depends on how severely the nerve cells were damaged. This cannot be tested or predicted before surgery. The surgery itself is a major operation with considerable risks, including the possibility of further neurological damage.

Occasionally the drainage tube will become blocked and another operation becomes necessary. Reduction in syrinx size on post-operative MRI usually corresponds with a good functional outcome. However, in the literature there is a reported decline in function in about 50% of patients within five years of the surgery. The cause of the decline is variable and ranges from recurrence of the syrinx, shunt malfunction, and scar tissue and tethering of the cord at the surgical site.

The sooner PTS can be diagnosed, the less damage it is likely to do. Thus, suspicious symptoms should

be discussed promptly with your doctor.

References:

- 1 Carroll AM, Brackenridge P. Post-traumatic syringomyelia: a review of the cases presenting in a regional spinal injuries unit in the north east of England over a 5-year period. *Spine* 2005;30(10):1206-10.
- 2 Rossier AB, Foo D, Shillito J, et al. Post-traumatic syringomyelia: incidence, clinical presentation, electrophysiological studies, syrinx protein and results of conservative and operative treatment. *Brain* 1985;108:439-461.
- 3 Peerless SJ, Durward QJ. Management of syringomyelia: a pathophysiological approach. *Clin Neurosurg* 1983;30:531-576.
- 4 Sgouros S, Williams B. Management and outcome of posttraumatic syringomyelia. *J Neurosurg* 1996;85:197-205.
- 5 Laxton AW, Perrin RG. Corpectomy for the treatment of posttraumatic syringomyelia. Report of four cases and review of the literature. *Journal of Neurosurgery* *Spine* 2006;4(2):174-8.

Up Close and Personal: Maryanne Caldwell

This is the thirteenth in a series of articles profiling the ASCC Case Managers.



Maryanne Caldwell joined ASCC in December 2006. She works out of the Fayetteville office and provides Case Management Services to approximately 200 individuals in Benton, Carroll, Madison and Washington Counties.

The past year has been very hectic for Maryanne. Besides relocating to Fayetteville to begin a new career, Maryanne married Matt Caldwell in March and then they moved to Eureka Springs. Despite these changes in her life, she has adapted well to her new position as an ASCC Case Manager. According to Client Services Administrator Patti Rogers, "Maryanne is very capable and is a staunch advocate for her clients. ASCC is very excited to have someone with her experience and qualifications."

Maryanne has enrolled in UA and is working on her Masters in Rehabilitation Counseling. She obtained her Bachelors degree in Sociology from the University of South Carolina. Her previous work experience includes working with the State of South Carolina Medicaid Waiver program for persons with spinal cord injuries and head injuries. She also has an excellent background in the durable medical equipment field. "It is not often ASCC is able to hire someone with experience working with individuals with spinal cord disabilities, so we are very fortunate," Ms. Rogers commented.

In her spare time, Maryanne loves being outdoors with Matt. In fact, they spent part of their honeymoon backpacking in Hawaii!

PROFILE:

Date And Place Of Birth: March 2, 1977, in Charleston, SC

Family Members: My husband, Matt Caldwell, and a neurotic dog, Hatfield (who has a natural Mohawk)

If I Did Not Live In Eureka Springs, I Would Want To Be: In the Appalachian Mountains of North Carolina.

I Absolutely Will Not Eat: Collard Greens . . . they smell like dirty feet and taste like them too.

One Thing People Would Find Surprising About Me Is: I was a competitive shag dancer (not Austin Powers—the South Carolina state dance) since I was 15 years old. I competed with the same partner, Patrick, for six years.

I Have A Need To Be: Outside—it soothes my soul.

My Favorite Movie Is: *Shag* (with Phoebe Cates, Scott Coffey, Bridget Fonda and Annabeth Gish).

My Favorite Song Is: I am a big fan of beach music, so my favorite song is *Carolina Girls* by General Johnson & Chairman of the Board.

I Am Most Comfortable With People Who: Have a positive outlook on life and are encouraging.

My Favorite Pastimes Are: Kayaking, canoeing, backpacking, hiking, sitting on the beach in Folly or Isle of Palms, South Carolina and, last but not least, rocking on my grandparent's front porch eating boiled peanuts and drinking sweet tea.

The Best Advice I Ever Received Was: "Never take 'no' from someone who is not authorized to give you a no!"

My Favorite Saying Is: "That which does not kill you will make you stronger." And as my grandmother says, "When God closes a door, he will open a window."

I Knew I Was Grown Up When: My daddy would no longer pay my bills.

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Backpack all 1,200 miles of the Appalachian Trail.

One Word To Sum Me Up: Compassionate

Changing Status . . . Again

As the population of people with spinal cord disabilities in Arkansas grows (by 176 in fiscal year 2006), the caseload of the Arkansas Spinal Cord Commission (ASCC) grows. Unfortunately, the staff size hasn't grown with the caseload! As we begin 2007, each ASCC Case Manager has responsibility for an average of 185 cases and most cover three to ten counties! That takes some time management skills, to be all the places you are needed at the same time.

In order to keep track of the clients on each caseload, ASCC has "status codes" or groupings based on client need. Typically, those with new injuries or who have little or no family or who live in a nursing home get more of our time and attention, while others have virtually no needs and we work on a "call us if you need us" basis.

Over the past year ASCC has been evaluating our services, our funding and the needs of our clients and families. While we still believe home visits are important, for some folks they are not needed or wanted, and for others finding you at home is difficult. The task force

appointed to look at these issues did research, collected information and made recommendations to administration and finally to the members of the Commission for their approval.

Our "new system" went into effect on January 1, 2007. **For most clients, you won't notice any change in our services.** For others, you may receive a phone call instead of a visit from your Case Manager, but **they will visit whenever you request it.** In addition, in order to do a better job of keeping track of your needs, once a year during a call or visit, we will be collecting some information about you, your health status and the services you use. That will help your Case Manager help you!

These changes are being made to improve ASCC services. We feel that it will optimize the services our Case Managers provide. If you have a concern about your ASCC services, please call and talk with your Case Manager. If that doesn't resolve it, contact Client Services Administrator Patti Rogers or Executive Director Cheryl Vines at **1-800-459-1517**.

world. For years after retirement, her patients called for her advice.

Shirley McCluer had high expectations—of herself, her colleagues and her patients. **She made you want to achieve**, and she often rewarded you with a gold star for achieving a goal. After retirement, she continued to teach a tai chi class and a computer class for senior citizens and she pursued her love of genealogy. She is survived by her sister, Jody Boyd of Jena, LA, and a host of nieces and nephews.

The members and staff of ASCC will never forget Dr. Shirley McCluer. Arkansas is a better place for her time here.

Carolyn Boyles

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A literature review revealed bacterial studies that showed that D-Mannose in the urine can decrease the adhesion of some E. Coli and Kleb. Pneumoniae to the bladder wall and thus there is the potential for decreasing the number of bladder infections. I then looked at several online web sites promoting and selling D-Mannose supplements. They only offered personal testimonies and quoted animal and bacterial studies as evidence. None of the quoted research studies had used the oral supplements being sold.

*The bottom line is that **there are no good clinical trials or scientific research studies that support or refute the use of D-Mannose.** Our experience with similar product cranberry supplements has been disappointing. When cranberry supplements were assessed using rigorous scientific studies, they did not decrease the incidence or symptoms of bladder infections.¹*

*My advice to patients interested in trying D-Mannose or who continue to use cranberry supplements is to **weigh the risks vs. the benefits.** Use of D-Mannose, basically a sugar pill, has low medical risk. The cost of buying and taking the pill is a risk determined by your wallet and the amount of time on your schedule. The benefit of decreased bladder infections is an unknown, but I have several patients who swear that the cranberry supplements help them and, since the risk is low, I do not discourage them with the scientific facts, since there maybe something about their body chemistry which may make it more effective for them than the general public."*

Reference:

1. Waites KB, Canupp KC, Armstrong S, DeVivo MJ. Effect of cranberry extract on bacteriuria and pyuria in persons with neurogenic bladder secondary to spinal cord injury. *J Spinal Cord Med.* 2004;27(1):35-40.

Shirley McCluer

Continued from page 1

sible for their care—they knew their bodies better than anyone. A true advocate, she was one of the people Richard Petty and Marilyn Cox called when a group of advocates started the first independent living center in Arkansas, now called Mainstream.

Dr. McCluer retired from UAMS in 1993. She spent the last decade of her career writing, teaching, and developing resources so that she could pass on what she had learned in her long career to those who could use it. Many of her articles, fact sheets and emergency cards have been reprinted around the



The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you “should have done but didn’t.”

A second opinion on the topic, client Carolyn Boyles shares her secret of avoiding urinary tract infections (UTIs).

I think we can all sympathize with persons with UTIs, disabled or not. I don’t doubt that Mr. Green’s regimen on Methenam [see *The Squeaky Wheel*, October 2006] has done the trick for him, but I have concerns about being on an antibiotic for long periods of time and the possible development of antibiotic-resistant bacteria. Instead of using an antibiotic to prevent UTIs, I take two D-Mannose supplements every day. D-Mannose does not require a

prescription but may have to be ordered by mail depending on what health food stores are near you. D-Mannose is the active ingredient in a highly marketed product called Mannose Magic®. D-Mannose is cheaper and the particular supplement I buy actually is more potent than the dosages in Mannose Magic®. I pay about \$16 a bottle plus shipping instead of \$25 a bottle for Mannose Magic® plus shipping. That’s my two cents’ worth.

Editor’s Note: Again, I checked with Tom Kiser, M.D., ASCC Medical Director, who said, “One of the things I enjoy about the practice of medicine is talking with patients and learning how they are managing their SCI. The use of D-Mannose supplement, an over-the-counter medication, to prevent bladder infections is a new idea to me. It has not been brought up by my patients in clinic and it is not being discussed at SCI meetings.

Continued on page 7 - see “Carolyn Boyles”

We invite you to send in your helpful hint—your bit of “grease.” Contact your ASCC Case Manager, write us at *Spinal Courier*, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at courier@arspinalcord.org and make the subject line read **“Attention: Squeaky Wheel.”**

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